The Elim Care Groups: A Community Project for the Control of Trachoma

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Introduction

The Far North of South Africa, where Elim Hospital is situated, has been known as the trachoma belt. The disease was the main cause of preventable blindness in the area. In the 1970s the local epidemiological pattern of trachoma was studied in the region served by Elim Hospital.[1] Several randomised population surveys were carried out, and the results indicated that preschool children aged 2–4 years represented the main reservoir of infection in the community; that spontaneous cure tended to occur at school-going age; and that repeated re-infections later in life eventually led to blinding complications, especially in women tending young children (Fig.1). Men who were absent from their homes most of the time as migrant labourers, were much less affected. These findings explained why many years of school treatment schemes had not reduced the overall prevalence of intense trachoma and its complications in the population, as preschool children continued to spread the disease. Hence, measures to control trachoma should have two main goals. First, to reduce the infective load in the community by treating young children with tetracycline eye ointment. Second, to prevent re-infection by motivating mothers to improve hygienic conditions in their homes. This rationale led us to involve the communities themselves in the control of trachoma.

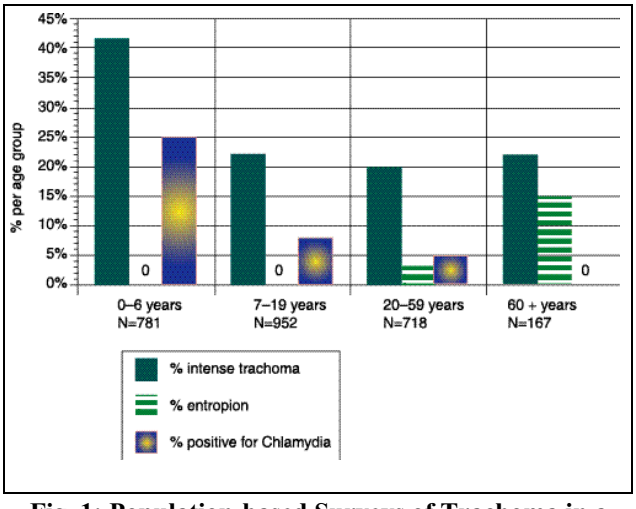

Fig. 1: Population-based Surveys of Trachoma in a Rural South African Community

Approaching the Community

The project was set up in 1976 to establish groups in villages in the area around the hospital. Because the majority of the men were working in distant cities, the groups, later called Care Groups, were mostly joined by women. The Project Co-ordinator, based in the hospital, was assisted by a number of Motivators. The idea spread very rapidly, and by the end of the first year 24 of the approximately 80 settlements served by the hospital already had a Care Group.

Trachoma was well known in the area, and the people were concerned about it. Several popular beliefs about the disease, handed down over many generations, testify to this concern. Some examples illustrate the remarkably accurate observations, which have become disguised in so-called superstition. For example, people insist that every child should have 'mavoni', i.e., discharging eyes in childhood, in order to see well later in life. In fact, the majority of children acquire trachoma within the first three years of life, and by the time they go to school the disease has usually resolved without affecting vision. Also, it was said that a multiparous woman who fails to inform her mother-in-law about her new pregnancy will get eye trouble after the birth of the child and her mother-in-law will get 'xinyeku', that is entropion, or will go blind ('mahlo ya xidzhwele'). Obviously people have observed that blinding complications occur most frequently in large families with many children – a fact we also found in our surveys.[2] Finally, the word 'xinyeku' is also used to describe a careless, poor and untidy woman, i.e., entropion has long been associated with poor hygienic conditions favouring re-infection with *Clamydia trachomatis*.

Health education could thus be built upon traditional wisdom, and the feeling that their ideas were respected won the people's trust and interest. Mothers were keen to learn more about the nature and spread of trachoma in order to protect their own and their neighbour's children from infection. Thus, starting in three villages, interested women joined together to form Groups of unpaid volunteers. Their aim was to improve health and the quality of life in their homes and in their community. In most cases they started with trachoma and later moved on to general health and development.

Good standards of personal hygiene
Photo: Erika Sutter

The Groups chose their own steering committees which formed the liaison between the Groups and the hospital-based project leadership, i.e., the Co-ordinator and the Care Group Motivators. The Motivators visited the Groups regularly for ongoing health education and discussions. Alternatively, the Clinic Nurse or the Community Health Worker took care of the local Group.

The Training of Care Groups

Working with communities is bound up with a long learning process for organisers, facilitators and the people in the community. There is no room here to discuss this process at length.[3] Instead we shall confine ourselves to the methods and outcome of health education concerning trachoma.

Having tried both nurses and less educated assistant nurses as Care Group Motivators, we found that the latter were suited for this particular task. They were local people with limited schooling, and were thus culturally nearer to the villagers and related easily to them. In many respects they were more innovative than their seniors who had had more formal education. However, even these Motivators had first to go through a lengthy process of 'un-learning' to become

proficient health educators, because their own educational experience had been authoritarian one-way instruction. Then, they learnt the skills of leading group discussions, awareness building and encouraging the women to find their own solutions to their problems. There was all too little guidance for them in the beginning, but in spite of this, most managed remarkably well to improve their methods. They soon realised that routine health talks did not change people's behaviour. The women needed ample time to absorb the message, ask questions, argue and discuss until every one understood and agreed on action to be taken. In addition, grandmothers had to be drawn in and given an opportunity to voice their opinion. On their own initiative, Motivators visited old folk in villages, discussed with them their traditional way of life and asked them for advice. This good relationship made it easier for young mothers to introduce new methods in their homes, where traditionally the mother-in-law is dominant. This kind of give and take is only possible in smaller groups like the Care Groups, and is more promising than health lectures to larger audiences where there is little personal commitment.

Care Group members, in their turn, were well motivated to apply their new knowledge, because most were in some way affected by the problem trachoma caused, and, moreover, they had struggled in their discussions to find their own solutions. They also discussed their difficulties amongst themselves and helped each other to introduce the necessary change in their homes. Thus, the famous KAP-gap (Knowledge, Attitude, Practice) was overcome with relative ease, at least when changes were within the limited financial and social possibilities of the Group members.

As mentioned earlier, treating young children and avoiding re-infections were the cornerstones of the control of blinding trachoma. Since the supply of tetracycline eye ointment was seldom adequate, we were forced to limit treatment to a few selected settlements. The main emphasis was therefore directed towards the improvement of hygienic practices. These included digging refuse pits and erecting toilets to reduce the fly population, and washing face and hands frequently. At that time people had already stopped washing themselves with their bare hands and had adopted the 'more distinguished' Western face cloths. In practice one single cloth was shared by the whole household, thus transmitting *Chlamydia trachomatis* from eye-to-eye. The health message had, therefore, to stress the use of individual cloths – any piece of rag would do, as long as it was clean.

In addition to health education for disease prevention and health promotion, the Group members were also taught to instil eye ointment. When shown what trachoma looks like they too wanted to learn to evert the upper eyelid so that they could identify cases in their neighbourhood. After having verified that they were careful about washing their hands each time before touching an eye, and performed the procedure gently and correctly, we allowed them to go ahead with case finding. This was a great encouragement to their self-confidence.

Trachoma Control by the Care Groups in their Communities

The Groups understood that keeping their own homesteads clean was no guarantee of avoiding infection as long as the rest of the village did not do the same. It was, therefore, very important to share their new knowledge with everyone else in their community. Each Group developed its own method of communication. Most found that it was best to make home visits in small groups where they could support each other and were better received by the villagers than when they went individually. Other Groups made up their own health songs and went singing and dancing through the village, arousing the curiosity of the villagers, who then joined the dancers. When the crowd was big enough Group members told the audience what they had learnt. At many festive occasions in the community, Care Groups performed sketches about health. Some Groups decided on their own to visit the local school and instruct and examine the school children, and others talked to waiting mothers at the child health clinic.

In the beginning people were not sure whether they could trust a fellow villager who had as little school education as they had or was even illiterate. But soon they realised that these women had learnt much from their Motivators, and so people began to listen to the Care Groups. The health messages were easy to understand, because they were practical, addressed common communityproblemsandweredelivered in the villager's every day language. Furthermore, people could watch progress made in the homesteads where Care Group members were practising what they had learnt.

Care Group members were no different to the rest of their community, and struggled like the others to survive under the prevailing conditions of poverty and lack of infrastructure, water, fuel and jobs. Their example was thus made more convincing, having significant influence in the community, so that the villagers felt motivated to compete with their neighbouring Care Group members. In our experience Care Group members proved to be more believable and more successful than professional health workers with higher educational standards, who came from outside the community, and after the job was done returned to homes with running water, bathroom and toilet.

The health messages spread fast throughout the communities. After about a year most people understood the dangers of trachoma, how it was transmitted and what to do for its prevention. Many villagersbegantosetnewpriorities,especially for the proper use of the little water which was available. As they became conscious about the importance of face washing, water was set aside for this purpose, and afterwards used to water the vegetables. Refusepitsweredug,andsometoiletswere erected, though too few, because material was too expensive. Even in very poor settlements the appearance of the homesteads improved. Fig. 2 shows the effect Care Groups had in their communities on hygienic practices and on knowledge about trachoma.[4]

Although the Groups' activities were predominantly preventive and promotive, according to their slogan, 'Cleanliness is the best medicine', their message had to be supported by curative care when necessary. The occasional supply of tetracycline eye ointment to the Groups was always encouraging, for both the Groups and the community, because they could then actually carry out treatment. In addition, the hospital strengthened the Care Groups' credibility by a two-way referral system.

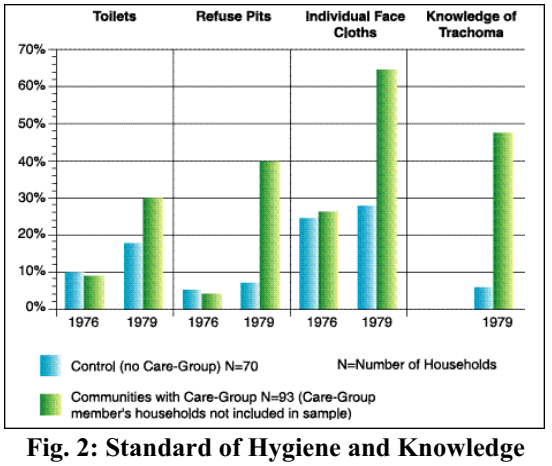

Fig. 2: Standard of Hygiene and Knowledge about Spread of Trachoma before (1976) and after Care Group Activity (1979)

Groups were allowed to refer patients to the clinic or to the eye hospital for treatment, and the hospital referred trachoma cases to the patients' local Care Group for further health education. The same system was later used for malnourished children. In a few places where the prevalence of trachoma was especially high, mass treatment through the local Care Group was organised to cover the whole community. But even with no, or only occasional treatment, prevalence decreased significantly in settlements where Care Groups were active, while there was no change in comparable villages which had no Group.[4]

After 3–4 years the Groups abandoned their preoccupation with trachoma, as they were satisfied with the results of their campaign, and turned to general health care, vegetable gardening and community development. Our fear, that the incidence of trachoma could rise again when the Groups discontinued their specific preventive activities against the disease, was not substantiated. On the contrary, its prevalence continued to fall.[5] This is demonstrated in Fig.3, where all population surveys on trachoma in the area where Care Groups operated have been summarised. After 5 to 10 years trachoma was no longer blinding, and had ceased to be a public health problem. Accordingly, patients with entropion presenting at the hospital had become rare. This development was surprising, as unemployment and poverty in the area was rather on the increase. Other factors may also have contributed to the control of the disease, such as improved water supply and a general change in people's attitudes, which meant that despite low incomes, better housing and improved hygienic standards were considered to be important. Unfortunately, it has not been possible to perform control studies in comparable regions which had no Care Groups,toexcludeconfounding factors.

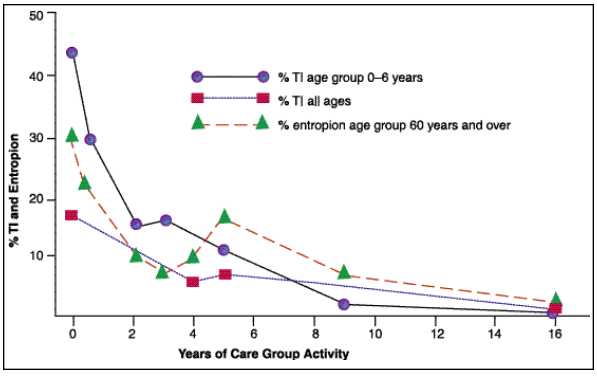

Fig. 3: Prevalence of Trachoma (TI) and Entropion in Relation to the Duration of Care Group Activity in the North of South Africa (1976–1995)

Conclusion

The impact of Care Group activity on the improvement of health factors such as personal and environmental hygienic conditions or the prevalence of trachoma has been measured, and proved to be statistically significant. However, social and human values which determine the quality of life, even more than health does, cannot be measured and expressed in actual figures. Over the years we observed many remarkable changes in the Care Group members' attitudes to themselves and their communities. They discovered their skills as health advisors, in problem solving and in leadership, and experienced that as a Group they were strong and could achieve much. This boosted their self-confidence and helped them to regain their human dignity as Black rural women, which the discriminatory tribal and apartheid society had denied them.

Now, more than 20 years since its beginning, the Care Group Project is still thriving and continues to adapt to the changing needs.[6] There are Care Groups in almost every settlement in the region, amounting to approximately 250 Groups with a total of 10,000 women. The Project differs from the majority of other community health institutions in its emphasis on Group action rather than individual health workers. Such a system is more stable, especially as the Groups are networking with each other, aided by strong and capable regional management teams composed of Care Group members, who have taken over responsibility for the Groups in their area. Thus, variation in motivation or changing interests can more easily be accommodated. The continuous presence of the Groups and the size and popularity of the movement have contributed to an ongoing high level of health consciousness in the population.

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Suppurative Keratitis

AK Leck, MM Matheson, J Heritage

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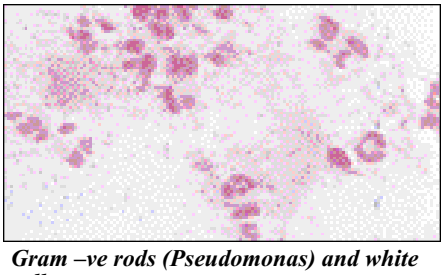

Gram –ve rods (Pseudomonas) and white cells

Photo: Melville Matheson

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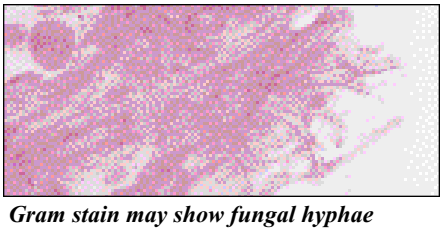

Gram stain may show fungal hyphae

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